

Documentation Guide

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This **Documentation Guide** has been developed and provided by the Alzheimer's Association for those who have a need to record evidence of a person's declining ability to function on a job or in a daily life situation.

This **Guide** is not a substitute for diagnosis. A comprehensive assessment for Alzheimer's disease always includes a thorough medical evaluation. The information you record here will be helpful when you are asked about change in the patient. This information may be helpful when you meet with physicians, respite care program coordinators or other long term care providers, as well as private insurance and Social Security Examiners reviewing for disability benefits.

The Guide contains:

- Examples of Changes in Abilities
- Social Security Disability Information
- A Personal Profile Form
- A Documentation Diary Form
- Medical History Form

This **Guide** has been designed to assist you in recording your observations and to provide concrete documentation of changes in the person's ability to function in their accustomed manner. To do so, you will need to 1) complete the **Personal Profile** and then 2) periodically log, in diary fashion, specific behaviors which seem out of the ordinary or other than normal. Include dates of incidents as they occur. The **Documentation Diary** is a format for you to use, you may need to continue on additional paper.

Name _____

Diagnosis date _____

Personal Profile date (prior to first symptoms) _____

Family _____

Written by _____ **Date** _____

Excess disabilities (other physical and sensory impairments — i.e. eyesight hearing diabetes high blood pressure etc.) _____

Personal Profile

In order to document a change in abilities that interferes with everyday function, it is necessary to have a basis for comparison. When complete, the **Personal Profile** will provide a word picture or baseline profile about the person and his/her **Functional Abilities** which were typical of behavior prior to the time of the Alzheimer's disease diagnosis or disturbing behavioral symptoms.

Person's Employer _____
Name _____ **Telephone Number** _____

Date person stopped working (if applicable) _____

Social Security Number _____

Date of Birth _____

■ **Examples
of Possible
Changes in
Function—
Loss of
Abilities**

1) Memory impairment

- a) Inability to remember important information (an event, meeting, trip, child or grandchild). More than occasional forgetfulness.
- b) Inability to remember/recall well-learned information and/or inability to learn new information (how to operate a familiar machine - using a telephone).
- c) Perseveration - repetitive movements or persistence in statements or questions (tapping, folding, hand-wringing or saying a phrase over and over).

2) Disorientation to time

- a) Dressing inappropriately for the season or weather (heavy coat in very hot summer).
- b) Missing important appointments or deadlines.

3) Disorientation to place

- a) Getting lost in familiar surroundings (losing the way home from the workplace which has been the same for many years, possible unexplained absences where person has difficulty finding directions from one place to another).
- b) Inability to orient in unfamiliar place (finding the bathroom).

4) Impairment of judgment

- a) **A** change in decision making ability (poor household decisions or business/ financial decisions).
- b) Difficulty in concentration.
- c) Inappropriate judgment (calling police for unwarranted suspicions).
- d) Inappropriate control of impulses (exhibitionism, sexually inappropriate remarks or actions, change in toileting habits such as urinating on street, marked change in buying or saving habits).

5) language impairment

- a) Change in ability to communicate effectively.
- b) Marked change in vocabulary (soft-spoken words to harsh profanity).
- c) Change in language skills (a lot of searching for words, particularly nouns).
- d) Conversations which are incomprehensible, irrelevant or where person loses train of thought.
- e) Person has difficulty understanding what is said, may become argumentative or perhaps combative.
- f) Person tends to repeat the same words or phrases.

6) Decline in capabilities and routine activities of daily living

- a) Change in eating or dietary habits (dramatic change - more or less - in preference for sweets, salty foods or condiments).
- b) Changes in sleep patterns.
- c) Significant change in the way person dresses or grooms (not bathing).
- d) Regressive change in table manners (using fingers or eating directly from serving bowls).
- e) Marked change in reading habits (not reading newspaper).
- f) Marked change in writing abilities (the mechanics of writing evidenced in checkbook from one year to another - name not signed in designated area).
- g) Changes in ability to do simple perceptual tasks (unlock door or familiar tasks such as paying bills, evidenced in non-payment or duplicate payment of bills which were usually paid on time).
- h) Loss of measured intellectual ability (evidenced from former records; school, military, employment testing, films, artwork or written material).
- i) Marked change or difference in interests and activities.

- 7) Change in personality and/or marked difficulty maintaining social function**
 - a) Noticeable personality change (confident to indecisive. extroverted to withdrawn, accommodating to demanding or vice versa).
 - b) Difficulty in maintaining friends and former social relationships.
 - c) Increased dependency (independent to clingy).
- 8) Changes in expressions of feelings**
 - a) Withdrawal or disassociation from activities and/or situations.
 - b) Inappropriate or unwarranted anger, frequent crying in one who never or rarely cried.
 - c) Dramatic mood swings from happy to sad. stubborn or docile or vice versa.
- 9) Thinking disturbances**
 - a) Unwarranted suspiciousness (thinking food is poisoned or that people are stealing things).
 - b) Seeing/hearing/touching things and/or people that are not there, imaginary friends or enemies (in mirror or tv).
 - c) Imaginary powers such as invincibility.
- 10) Job performance**
 - a) Marked change in vocational interest.
 - b) Missed deadlines or appointments.
 - c) Reduced efficiency on the job.
 - d) Catastrophic reactions to problem situations.
- 11) Other influences**
 - a) Marked change in acceptance of physical limitations.
 - b) Drug or alcohol abuse.
 - c) Marked changed because of other illness.

Social Security makes disability payments under two programs: 1) the Social Security Disability Insurance (SSDI) program; and 2) the Supplemental Security Income (SSI) program, which provides disability payments for people who have very low income and have not worked long enough to be eligible for SSI. For both programs, the medical and functional requirements for eligibility are the same. Decisions about whether a person meets the medical and functional eligibility requirements for SSDI and SSI are made by the Social Security Administration using many sources of information, including information from the person, the person's family, the person's doctor, and hospitals and other institutions that have provided care for the person. Completing the Personal Profile Form that follows can help you document changes in the person's functioning and ability to work. The Personal Profile Form is not a Social Security Administration form, but the completed form will be useful to you in talking with health care professionals and Social Security Administration staff who are involved in documenting and making decisions about the person's eligibility for disability payments.

The Social Security Administration also has pamphlets and representatives that can help you understand the eligibility requirements for SSDI and SSI and apply for disability payments. You may call toll-free, 1-800-772-1213 (TTY, 1-800-325-0778) or visit the Social Security Administration's website, www.ssa.gov.

If a person's application for disability payments is denied, he or she has a right to appeal that decision. Because of the way Alzheimer's disease and other diseases progress, the frequent uncertainty about date of onset, and other characteristics of these conditions, it may be difficult to determine whether the person is eligible, and disability applications may be wrongly denied. It is advisable to appeal such decisions. Professional advice about appealing a disability decision can be obtained from experienced attorneys. Your local chapter or the National Organization of Social Security Claimant's Representatives (1-800-431-2804) can be contacted for information or to direct you to an attorney who specializes in Social Security law.

■ **Personal Profile**

This Personal Profile is designed to **describe your patient when he or she was not ill**. The categories queried are provided as a guide only, not all patients will experience changes in all these areas. It should also be noted that the order of these categories does not necessarily reflect the progression of the disease.

Describe the individual's abilities and skills. Please include details about the outlined functional abilities, answering the questions and **giving examples to illustrate each area**.

1. Memory

- a) What evidence can you give that the person had ability to remember important information?
- b) In what way was he/she able to recall well-learned information?

2. Orientation to time

- a) How did the person show awareness of time, date and season'?
- b) What were the person's habits regarding appointments and deadlines?

3. Orientation to place

- a) How did the person respond to orienting in various places, finding directions, etc.?
- b) How did the person make adjustments to changes in environments?

4. Judgment

- a) Give an example of the person's former ability to make choices and decisions.
- b) How did the person react to complex situations?
- c) In what ways did the person use appropriate judgment'?
- d) Did the person have appropriate control of impulses (sexual, personal such as toileting, buying, and saving?)

5. Language

- a) Explain how the person was able to communicate effectively.
- b) What was the person's manner of talking (vocabulary, use of profanity)?
- c) Can you give evidence of the person's appropriate use of words and names?
- d) Was the person usually able to be understood?
- e) Can you tell about the person's ability to understand spoken communication?
- f) What were the person's language habits regarding repetition of words or phrases?

6. Capabilities and activities of daily living

- a) What were patterns of daily routine, including sleep, eating and dietary habits?
- b) Describe the person's former natural dress and grooming.
- c) What characterized personal manners (courtesy, politeness, table manners)?
- d) What were the person's reading habits, writing skills including creativeness and mechanics (spelling, mathematics and handwriting)?
- e) Describe problem solving skills. Was there appropriate understanding of tasks?
- f) What was the person's intellectual ability? (Include sources of measured tests.)
- g) What were the person's interests, business experience activities and education achievements?

7. Sociability

- a) How would you describe the person's personality?
- b) What were the person's relationships with other people? Did he/she have many friends? Did he/she send letters and make phone calls?
- c) How would you characterize the person's sense of independence?

8. Expression of feelings

- a) How did the person tend to handle or express his/her feelings?
- b) Indicate whether the person was prone to emotional outbursts (anger, crying).
- c) Describe if the person had dramatic mood changes or disturbances.

9. Thinking

- a) Show how the person had the ability to concentrate, plan and think things through.
- b) Describe how the person was able to fulfill required roles.

10. Job performance

- a) What was the person's vocation, occupation and/or former occupations?
- b) What was job performance? How did the person react to stresses of deadlines?
- c) Describe the person's efficiency on the job.
- d) How did the person react to complex problems on the job?

11. Other influences

- a) Comment on any factors that may have affected behavior, such as sensory loss - hearing or sight.
- b) What was the person's customary use of drugs and medications including alcohol?
- c) Has the person any other illnesses? Describe, telling what they started.
- d) Do you have anything else to add?

■ **Documentation Diary Form**

| <i>Date</i> | <i>Brief description of event indicating changes in function, impairment of abilities and retained abilities</i> |
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